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ABSTRACT

The report is based on a 1982 conference on the status of independent living programs, community based programs run by disabled persons to provide advocacy and support services to the disabled community. The philosophy of independent living is reviewed and its attributes of community responsiveness, provision of support services and advocacy, and leadership of disabled persons in program design and management are considered. The origins of the independent living/disability rights movement is traced from the 1960's up to current policy conflicts over the federalization of independent living under the rehabilitation system. Crises facing the independent living movement are examined, dealing with funding and funding development, leadership development and direction, organizational development and management, service delivery and community needs, and public relations, education, and community support. A final chapter offers recommendations for addressing five major needs: support and technical assistance in operations and management, development of strategies for networking and communications, leadership development and training, research and policy development in independent living, and long-term planning. (CL)

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Challenges Of Emerging Leadership:

Community Based Independent Living Programs And The Disability Rights Movement

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CHALLENGES OF EMERGING LEADERSHIP:

COMMUNITY BASED INDEPENDENT LIVING PROGRAMS AND THE DISABILITY RIGHTS MOVEMENT

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WASHINGTON, D.C.

CHALLENGES OF EMERGING LEADERSHIP:

COMMUNITY-BASED INDEPENDENT LIVING PROGRAMS AND THE DISABILITY RIGHTS MOVEMENT

A Report Produced by the Independent Living Leadership Strategies Project

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Preface

The origin of this report resides in several late night conversations in 1979 with Judy Heumann, Barry Bernstein, and Chris Palames. All were closely connected to independent living programs, and had had experience working with other program directors. All were concerned about the growth of the powerbase of disabled community activists and worried about how to maintain a sense of purpose between older community based independent living programs and new centers emerging with federal funds. Quick growth and funding cutbacks threatened the stability of programs. More so, communications across programs were limited, and maintaining a unified sense of purpose, value, and goals was becoming more difficult as directors struggled with day-to-day operations.

Over time, these conversations led to one with Jean Whitney, the Charles Stewart Mott Foundation program officer interested in independent living, and a grant to provide the Foundation with a status report on independent living programs. This report is that status report. It is, more importantly, a much larger effort to pull together the recommendations for future action of experienced program directors and others interested in independent living.

The report has been culled from a five-day, intensive meeting in East Lansing, Michigan in August 1982. The participants in the East Lansing conference came together to assess the state of the art of independent living. They were extremely candid with their comments, and they identified those areas that were particularly problemmatic. Thus, the text of this report tends to focus on issues and problems, and on solutions to those problems. It does not convey fully the tremendous impact that independent living programs have had on their communities, the high quality of services the programs offer their participants, or the range of expertise which exists in programs. Nor does it represent fully the methods which programs have used to resolve some of the problems identified. The reader of this report should understand this bias.

This report provides a basis for future action in five major areas: technical assistance, networking and communications, leadership development, research and policy analysis, and long-term planning. Work in each area is important if independent living programs and the disability rights movement are to continue their work to assist disabled persons.

To Judy Heumann, Barry Bernstein, and Chris Palames goes credit for conceiving of the idea and carrying out the planning over great distance. Margot Gold served ably and with little reward for coordinating the conference and laying out the program and conference materials. Marian Blackwell Stratton wrote the first conference draft and captured not only the conversations and tone of the meeting, but also its detail and its context. The final document is the result of discussion with the participants and writing and rewriting by Robert Funk, while major issues needing his time, attention, and energy continued to surface at the local and national levels. Finally, all of us thank Jean Whitney and the Charles Stewart Mott Foundation for taking a risk and providing support to Independent Living at a time when leadership and national assistance are greatly needed.

Lisa Walker
Institute for Educational Leadership

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CHALLENGES OF EMERGING LEADERSHIP: COMMUNITY BASED INDEPENDENT LIVING PROGRAMS AND THE DISABILITY RIGHTS MOVEMENT

Executive Summary

I. Introduction

- **Challenges of Emerging Leadership**, a report on the status of independent living programs, community based programs run by disabled persons to provide advocacy and support services to the disabled community, is based on the observations and discussion of program directors from across the country.

II. The Philosophy of Independent Living: Designing for Independence

- The independent living movement was formed by severely disabled persons who designed programs and coordinated community change to achieve independence despite limits in existing services.

- These programs were designed around three basic principles:

  — **Disabled persons design and run their own programs.** As such programs provide employment and volunteer opportunities which build skills for integration into the mainstream, peer role modeling which encourages other disabled persons to take risks and become self-reliant, and a community based support system which is a symbol of productivity for the broader community.

  — **Programs are community based and community responsive.** They meet the specific needs of their own local community and rely upon the community for continued leadership, staff recruitment, and support.

  — **Programs provide services and undertake advocacy for change in the broader community.** Advocacy broadens the avenues disabled persons can pursue within a community over time, and teaches self-advocacy skills.

III. Development of the Independent Living and Disability Rights Movements

- The true turning point in the emergence of disabled persons and independent living programs as an acknowledged political force came when the Carter Administration refused to issue regulations to implement Section 504, the key anti-discrimination law. The disabled community erupted in demonstrations around the country and in Washington, D.C., including a 28 day occupation of offices of the Department of Health, Education and Welfare in San Francisco. Leaders in the San Francisco occupation were disabled persons from the Center for Independent Living, a prototype of the new programs emerging as community based social action programs developed and run by disabled persons.

- The Berkeley model of independent living had been developed by former University of California severely disabled students who questioned prevailing thinking that the road to social integration and independence for disabled persons was through higher education. Acknowledging that disabled persons live within a physical, social, and economic environment which poses limitations which must be removed, the model offered services and self-determination to a wider range of persons in the community who had to learn to be self-advocates and could not assume higher education as the ultimate solution.

- The independent living programs formed at this time were unique. They were broad coalitions of disabled persons with different disabilities; they were focused on community change and disability rights; they were formed and run by disabled persons living within the community; they provided support to disabled persons regardless of age disability or severity.

- Programs were started in Boston, Houston, Ann Arbor, and other cities, and a second stage had begun as state rehabilitation agencies began experimenting with discretionary funds to create a variety of programs described as independent living programs.

- In 1978, passage of targeted federal legislation to support independent living programs (ILPs) both greatly expanded the number of programs, and produced models which do not meet the original goals of self-determination. Today, a total of 135 programs provide attendant care, housing referral, transportation, peer counseling, and other services designed to facilitate the integration of severely disabled adults into the mainstream of the social, economic, and political community. Dependent as they are on government funding, many of the new programs are in an awkward position as an advocacy force against the agency that funds them.

- The growth of programs stimulated by external funds and governed by state agencies and the federal government has underscored tensions existing within the professional and consumer communities over the goal of independent living. For rehabilitation professionals, independent living services were seen as an alternative form of services for disabled individuals for whom employment was not feasible. Today, their growth is beginning to threaten traditional rehabilitation services, and arguments continue to be put forward that they will lessen the emphasis on employment as a primary objective.

- For independent living proponents, ILPs are part of the process of achieving independence for disabled individuals; they teach self-support and advocacy, self-determination, and provide disabled individuals with both peer role models and avenues for development of pre-employment and employment skills and continued development. Rather than service delivery in the traditional sense, the independent living program is a support center for the disabled community for a wide range of services and needs, providing community based advocacy to further integration.

- **The conflict in perception about the goals of independent living programs is significant to the future of these programs. The lack of understanding of the broader purposes of these programs by the general public, state and federal agencies, funding sources, and parts of the disabled community has produced**

policy constraints which limit program effectiveness.

IV. Maintaining Independence: Operational Issues Confronting the Community Based Independent Living Movement

- The community based independent living movement is facing a crisis brought on by the rapid increase in programs, rapid growth within programs, and growth in demands by the disabled community. This situation has been exacerbated by reduced economic resources, public indifference, and the lack of a network support base across programs.

- **The most critical issue facing independent living programs is the lack of a stable and adequate base of funding.** At least 80% of the funds for independent living programs come from a single source: the federal/state vocational rehabilitation program. Support from a single source is not healthy, and when that source is a single program, the potential for pressure is maximized.

  Diversification of funding is necessary, but limited by: the current state of funding for social services and the fact that independent living is a "new kid" on the block, a lack of awareness and understanding by local government and private funders about disability, and the youth and inexperience of the programs in outreach and public relations.

  In fundraising development for independent living, a series of issues must be addressed. The image of disabled people as "deserving poor," dependent and helpless, must be changed so that priorities for funding change. Program directors need experience and training in fundraising. The Boards of programs must be reshaped or other mechanisms found to assist with fundraising. Programs must begin to explore alternate mechanisms for funding.

- **A second issue is leadership development and direction.** Disabled leaders must develop their own resource base, support mechanisms, and power structures which will allow them to continue to grow as a network of community based programs serving the disabled community and to maintain the integrity of their programs and goals. What is called for is a targeted effort to more fully develop the strengths and capabilities of disabled persons in their programs and across programs.

  Leadership development, thus, must be undertaken in the following areas: training of staff responsible to better utilize the resources of the community, balance outreach with advocacy strategies, and obtain assistance of outside groups; training in using skills, knowledge and resources of other independent living programs; development of linkages between independent living programs and organizations involved in other parts of the disability rights movement.

  To extend services to disabled persons, increase leadership ranks, and broaden the base of the independent living/ disability rights movement, independent living programs must develop strategies to expand involvement and service delivery to racial and ethnic minorities, women, disabled children and youth, and disabled older Americans. Linkages must also be formed with parents of

disabled children.

The issue of the role of the non-disabled in independent living programs must be addressed. The increasing tendency to hire non-disabled in leadership and management positions weakens leadership development within independent living programs, violates the basic principles by which independent living programs were formed, and undercuts the ability of programs to play a forceful role in building self-reliance in the disabled community.

- **Third, assistance in organizational development and management is needed.** Directors of independent living programs are faced with broad responsibilities and scant staff expertise. These areas include legal issues facing the corporation, board development and utilization, long-range organizational development, personnel and fiscal management, and development of program accountability measures which are appropriate to this program.

- **Fourth, planning must be begun to deal with the growth in demand for services and the fiscal constraints limiting expansion of services.** Review of what other programs (independent living and others) have done to respond at this stage of growth will be important to avoid increasing frustration.

- **Finally, independent living programs are both service providers and catalysts for community change. Their ability to educate the community and build strong relationships of support are critical to survival.** Relationships with the media, other disadvantaged groups, local and state officials, and the business community must be built.

V. Achieving Independence: Future Options and Strategies

- **Independent living programs are a base for developing skilled disabled community leaders, managers, and program administrators.** They are an exemplary system for helping the broader community understand the capabilities and needs of disabled persons. The dual system of services/advocacy has met the needs of the client population in ways traditional rehabilitation or social services programs have not.

- **Most importantly, these programs have been at the core of the political and civil rights movement of disabled persons.** Thus, their growth and continued survival is key to a broader set of issues relating to the integration of disabled persons into the social, political, and economic mainstream.

- **Growth of federal funding for independent living programs has been a blessing and a problem.** Continued disagreement over the dual goals of service/advocacy, the increasing dependence of programs on federal money, and cutbacks in other funding place programs in a very insecure position at the present time. Assistance from other funding sources (particularly in understanding the role of independent living programs in expanding opportunties for the disabled community) is critically important to reduce dependence on federal money.

- Funding is not the only problem. Independent living programs are young, most being less than four years old. Little exists to provide directors the

support and back-up they need to continue agency leadership in present turbulent times. A support system among programs is critically needed.

Recommendations

- **Support and Technical Assistance for Operations and Management**

To assist directors in handling day-to-day management problems, independent living programs need to develop a mechanism to provide assistance to their peers: identifying experts in other programs, providing on-site assistance, and trouble shooting to resolve problems which are causing difficulties at the program level.

This assistance network could shortcut many problems by developing from their own experience packages in key areas, such as: non-profit accounting, job descriptions for independent living programs. **This network must be developed from within the independent living and disability rights movement, managed and directed by disabled persons.**

- **Network Capability and Cross-Program Communications**

A networking capability needs to be developed which will address the needs of managers for information on day-to-day problems, as well as on longer-term organizational development issues. This communications network would address the following areas:

Information Sharing - creation and maintenance of a national disabled job bank, reporting on individual programs (e.g., extension of services to new client populations, successful community advocacy efforts, and changes in federal, state, and local law), and identification of expert resources.

Decisionmaking by Independent Living Programs as a Group - consensus building on priorities and standard setting for independent living programs (role of non-disabled persons, relationships with other community institutions, establishment and assistance to new programs), representation of the needs of independent living programs to the media, foundations, corporate funding sources, policymakers and the general public.

Future Planning Activities for Independent Living Programs - development of consortium funding, development of alternate methods of program support.

- **Leadership Development and Training**

A leadership development and training plan must be developed which focuses on improving skills for program and community activities, as well as skills to take on activities in the mainstream.

Such a plan would include: broadening skills for planning and management of independent living (fiscal and program management, public relations, legislative representation, leadership skills, fund development); recruitment

and training of new leaders (outreach to minority and underserved communities, outreach for start-up of new independent living programs); skill enhancement for existing directors (training in public management and public policy, development of internship and fellowship opportunities, short-term replacement of staff for sabbatical activity); linkage with other leaders (internships and fellowships with other disability rights organizations and with major institutions to enhance the credentials of disabled leaders).

- **Research, Policy Development, and Long-Term Planning**

A capacity needs to be developed within the independent living/disability rights movement to carry out long-term planning and policy development. This capacity would include policy development and applied research activities (e.g., attendant care programs, independent living programs in rural areas, involvement of the mentally retarded and mentally ill in independent living programs, removal of job disincentives from the social security system) and development activities (e.g., development of an effective method of evaluation, standards, and economic development options for independent living programs, data collection on programs and on the disabled community).

- **Long-Term Planning and Linkage with the Disability Rights Movement**

To assist the disabled community as a whole to meet its goals of social, economic and political participation in the broader community, a capacity for long term planning must be developed. Areas to be addressed are: the relationship between disability rights organizations and other similar disenfranchised groups, the development of a consensus on the steps to take to further the integration of disabled people, identification of activities to develop the disabled community as a political power base, and identification of the impact that changes in technology, economic development, and political/demographic forces will have on the broader based disability rights movement.

CHALLENGES OF EMERGING LEADERSHIP: COMMUNITY BASED INDEPENDENT LIVING PROGRAMS AND THE DISABILITY RIGHTS MOVEMENT

I. Introduction

In the summer of 1979, three independent living program directors1, attending a conference in Washington, D.C. on another topic, spent their evenings discussing their programs and independent living at the national level. It was the kind of discussion which they felt needed to occur more often. Many disabled leaders of local programs were becoming so preoccupied with day-to-day management and the struggle to meet immediate needs that they had no such opportunities to step back and examine their local efforts in the larger context of the independent living and disability rights movement.

They came to the conclusion that a mechanism was needed to support ongoing communication among disabled persons who were providing leadership in local programs, one which would allow them to tap each other for mutual support and collective action as well as to define and analyze the complex forces which would impact the growth and ultimate effectiveness of local programs.

The assistance of the Institute for Educational Leadership was enlisted in defining steps to move in this direction. Out of this collaboration, a proposal was prepared and submitted to the Charles Stewart Mott Foundation.

The resulting Independent Living Leadership Strategies Project was designed to meet two primary objectives:

1) Convene a group of individuals who were active in the development of the independent living movement to begin conversations necessary to produce a consensus on short-term and long-term strategies for continued survival and growth of the movement; and

2) Produce a report based upon those conversations which would express their sense of the significance of the independent living movement and the challenge facing disabled people and independent living programs if they are to fulfill their potential.

Initially, the intent was to limit the conference to ten persons from diverse programs who had extensive experience in running independent living programs. The agenda and issues would be set in consultation with a cross-section of program directors and would reflect a diversity of experience,

geography, and community values. However, as discussions were carried out throughout the country, it became apparent that this Project was generating great interest. A number of persons were willing to commit their own resources in order to attend the conference. Consequently, the original number was doubled to respond to this interest, while keeping the group small enough to maintain the character of a "working conference."

The Independent Living Leadership Strategies Conference was held on July 26-30, 1982, at the Kellogg Center of Michigan State University in East Lansing, Michigan. Twenty-one persons representing programs from all regions of the country attended the five-day, intensive working session. They were a diverse group of men and women, coming from rural as well as urban areas and representing programs serving culturally and ethnically heterogeneous populations.2

The five-day conference was a unique and valuable experience. Though each participant brought different personal experiences, skills, and focus to the conference agenda, they had much in common: all were disabled, all had assumed leadership positions, and all recognized the central role of disabled people in a movement whose goals are empowerment, self-determination, and dignity for a group of disenfranchised people.

The conference also provided the first opportunity for many of these individuals to meet and discuss the underlying beliefs, values, and aspirations which are of prime importance in determining the character and effectiveness of their programs.

The conference began with a consideration of the developmental histories of programs and the personal histories of the people who were the prime movers in establishing them. It was recognized that, to an unusual extent, the distinctive character of each independent living program is a function of the the personal experiences of its leaders.

Disabled people create or become involved in Independent Living programs in response to their frustrations in dealing with an unresponsive physical, social,

and economic environment. The relationships between their own personal experiences—particularly those of the leader—and the distinctive qualities of the local environment have significantly affected the eventual structure of each Independent Living Program, its service and advocacy strategies, and its general style.

The conference reviewed the current "state of the art," looking at how the programs are structured, various management styles, and service and advocacy strategies. Included in this look at the present was an examination of the role of independent living programs in the growing disability civil rights movement. Finally, the discussion turned to the future in an attempt to define both short- and long-term strategies to support the growth and stability of local programs while preserving their integrity.

The Independent Living Leadership Strategies Conference began the communication and understanding necessary for the development of a national network and support system for community based independent living programs. It also fostered an understanding of the role of independent living in the broader disability rights movement and the necessary role of disabled people in guiding the movement.

This report has three aims. First, it provides a brief discussion of the development of disabled-run independent living programs and their relationship to the disability civil rights movement. Second, it sets out the short-term needs which conference participants agreed are threatening the immediate viability of community based independent living programs. Finally, it discusses the options and strategies the participants believe are necessary for the future growth of the independent living/disability rights movement.

II. The Philosophy of Independent Living: Designing a Program for Independence

> "The dignity of risk is what the movement for independent living is all about. Without the possibility of failure, the disabled person is said to lack true independence and the mark of one's humanity--the right to choose for good and evil."3

Today, in part because of federal funding, the concept of independent

living has come to have many meanings4, and has been used to define many models of programs. Independent living programs provide services—for example, housing, attendant care, information and referral, advocacy, independent living skills training, and transportation. But an effective community based independent living program provides more than services; it has an overriding goal of empowerment and the right of self-determination for disabled individuals.

An article, published in 1978, by Gerben DeJong, sets out three major propositions that underlie the philosophical context of the community based independent living movement.5

They are:

- **Consumer Sovereignty** -- disabled persons, the actual consumers of the services, not professionals, are the best judges of their own interests. They should ultimately determine how services are organized on their behalf.
- **Self-reliance** -- disabled persons must rely primarily on their own resources and ingenuity to acquire the rights and benefits to which they are entitled.
- **Political and Economic Rights** -- disabled persons are entitled to pursue freely their interests in various political and economic arenas.

The independent living movement was originally formed in response to the needs of severely disabled persons who were being ignored by traditional services programs.6 They were individuals who were presented with the limited life options of institutionalization or dependency on family support because their employment potential either was not recognized or was grossly underestimated by the rehabilitation system. Through the independent living movement, these disabled persons designed programs and coordinated necessary advocacy efforts enabling them to achieve independence despite limits in the existing services system.

Achieving what had not been achieved by other service providers, they recognized that three elements were critical to designing and maintaining an effective community based independent living center. They are:7

- **Disabled People** directing the organizational design and management and involved in the evaluation and provision of

services;

- **Community Based** and **community responsive** programs; and
- **Provision of Services and Advocacy** to the community to enhance self-determination, empowerment, and independence.

Before discussing the individual elements, it is important to note that they are interdependent. An independent living program must display all three, not merely to meet an arbitrary definition, but in order to effectively promote the goals of the independent living movement.8

A. Disabled People—Leaders in Program Design and Management

A basic premise of the community based independent living movement is that disabled people best understand their needs and the needs of their communities.9 This assumption was key to development of independent living centers in the early 1970's and was incorporated in federal legislation in 1978.10 Independent living programs run by disabled people meet other goals beyond merely better understanding of and ability to meet service needs of the disabled community. These include:

- Employment and volunteer opportunities that develop the skills and self-reliance necessary for integration into the social and economic mainstream;
- Peer role modeling that encourages others to take risks, develop skills, and become self-reliant; and
- Operation of a community based operation that serves as a source of support and pride to disabled people in the community and as a symbol of productivity and self-reliance for the broader social and economic community.

Though the concept of disabled people developing and managing programs may seem to be fundamental and obvious for community based support services and leadership development programs in other human services areas, it was in fact revolutionary in the early 1970's as applied to disabled persons. Even today it is the subject of considerable debate.11 The debate centers on whether or not a community based program can effectively pursue the support services and leadership development role if it is not directed and controlled by disabled people. Some believe direct control by disabled people is a necessity; others believe significant involvement by disabled people is sufficient.12 The Conference participants direct or were involved in programs that fit under both

sides of the debate. Yet, there is serious concern by disabled people that effective operation of an independent living center is seriously constrained if the organization is not responsive to, or a part of, the disabled community. In these instances, there is less of a feeling of community ownership by disabled people and confusion as to who defines priorities and evaluates effectiveness.

The debate will continue. It is clear, however, that disabled people believe direction and control of their own lives is the goal and, at the minimum, majority control and real involvement at all levels in a center is absolutely necessary for a program to be effective in providing assistance to disabled persons.

B. Community Based and Community Responsive

Independent living programs are established to meet the needs of and be responsive to their communities. A community can have varied geographic limits and population density.

The term "community responsive," as applied here, means the program is dependent upon individuals and resources within the local community for its continued leadership, staff needs, support, and survival.13 Community responsive programs must continue to respond creatively to new needs of the community in order to further the integration of disabled people into society.

C. Provision of Services and Advocacy

A community based independent living center has the dual function of providing necessary support services that promote self-determination and independence and undertaking advocacy within the broader community to promote the program's services, remove attitudinal and physical barriers, and promote the integration of disabled people into the social and economic mainstream.

In order to succeed in the broader community where their needs are not being represented, disabled persons must engage in advocacy efforts to maintain community based independent living programs. Advocacy can assume many forms. For some programs, it includes lobbying before a local or state government body

for financial support. For others, it is requesting a state rehabilitation agency to provide attendant care to enable severely disabled persons to maintain employment. For all programs, it is a service: teaching self-advocacy skills to enable disabled people to be more self-reliant and independent.

The support services provided by independent living programs include, among others, housing assistance and referral, attendant care, readers for the blind and interpreters for the deaf, peer counseling, financial and/or legal advocacy, community awareness, and barrier removal programs.[14] The method of service provision reflects the community's needs and in each instance is provided in a manner that promotes dignity, self-determination, and independence.

A major issue that is being debated within the independent living movement and within the professional establishment is the role of transitional and residential service programs. The model developed by the Center for Independent Living in Berkeley is a non-residential services and advocacy center that works to ensure disabled people can live outside of institutions. Transitional and residential programs are seen as a continued form of the problem that the independent living movement was designed to combat—institutions. Thus, development and growth of quasi-institutional models are seen as a direct threat to the ability of severely disabled people to make choices.

Further, the transitional and residential models are seen as a method of promoting the eventual non-residential living needs of certain disability groups. The experiences of many disabled people have been, however, that the transitional and residential programs do not promote self-reliance, but perpetuate lives of dependency and segregation, and the further growth of professional systems to "care for the handicapped."

This issue is one of serious debate and will intensify as independent living concepts are expanded to meet the needs of a broader spectrum of disabled people (mentally retarded, mentally impaired, and older Americans).

D. The Philosophy Defined

Clearly, these three elements are the foundation of independent living and define a philosophy which is wholly consistent with basic American political tenets. The participants in the conference developed a beginning "Philosophy of Independent Living" to elaborate on these values and to lay a basis for their future planning. The statement is reprinted in full in Appendix B. The preamble states:

Preamble

Among the foundations of our society is the acceptance of certain fundamental human rights. Independent Living is based on the belief that all individuals, including those with disabilities, shall have an equal opportunity to exercise those rights. The independent living movement shall affirm the basic human rights of disabled persons:

- To participate in the prerogatives and responsibilities of citizenship
- To equal employment opportunities
- To access to public facilities, transportation, and affordable housing for all disabled people
- To the supportive services necessary for employment opportunities and full participation in society
- To free, appropriate, and non-segregated education
- To bear, raise, and adopt children
- To full participation in the cultural, social, recreational, and economic life of the community
- To live in dignified independence outside of institutional settings

This philosophy addresses a basic concern of disabled leaders that the public understand effective community based independent living programs not as service providers but in their role as supporting and promoting the right of individual disabled persons to participate and contribute to society. Community based independent living programs, at their base, are a mechanism for leadership development, representation, and self-advocacy for a group of people that society, to date, has only seen as "patients" or "clients."

This role is misunderstood by persons within the independent living and disability rights movements, by disability professionals, by decisionmakers, and by the general public. This misunderstanding has impact on whether or not an entity called an independent living program is truly a community based, community responsive center. Failure to clarify this concept allows the public to deny the need for and acceptance of disabled people as leaders and directors of programs affecting their lives. Finally, the perception of independent living as "merely service providers" undercuts the future of independent living programs as catalysts for community and individual change, posing the option as eventual integration with the rehabilitation and social service systems as an alternative form of rehabilitation services.

III. Development of the Independent Living/Disability Rights Movement

It is difficult to point to the specific times or places where the independent living movement began. However, in a period of years from 1960 to the mid-1970's, we can describe a series of grassroots activities and federal policy changes that gave meaning to the movement we see today.15

The independent living/disability rights movement is rooted in the 1960's, though many of the essential policy and programmatic innovations which defined the formal structure we see today did not appear until well into the following decade. During the sixties, disabled people were profoundly influenced by the social and political upheaval which they witnessed. They identified with the struggles of other disenfranchised groups to achieve integration and meaningful equality of opportunity. They learned the tactics of litigation and the art of civil disobedience from other civil rights activists. They absorbed reform ideas from many sources—consumerism, self-help, de-medicalization, and de-institutionalization.16

One of the distinguishing marks of sixties' politics shared by many who swelled the ranks of the disability rights and independent living movements was an emphasis on personal transformation—changes of consciousness—preceeding and underpinning social activism. Disabled people had to achieve a dramatically new and positive valuation of themselves as a group as a pre-condition to effective organizing in pursuit of specific programs and policies. A critical aspect of

this process of rethinking disability was discarding psychologically the sectarianism which had long fragmented disabled people into so many subgroups—the blind, spinal cord injured, retarded, post-polio, etc. From these experiences, many disabled individuals emerged for the first time with a sense of themselves as members of a unique and valuable community, a sense supported by their comprehension that they had the right—hitherto denied—to participate as fully equal members of American society.

One remarkable fact, viewed in retrospect, was the large number of disabled individuals, many of whom were substantially isolated, preparing to act along similar lines. The implication of their newly politicized perspective on disability issues was that real reform could be assured only by the development of a broad-based coalition of disabled people throughout the United States who demanded both fundamental national policy reforms and community based support services that would permit them to break from the tradition of dependency and institutionalization and live as part of the social and economic community.

A. Changes in National Disability Policy

At the national level, revolutionary reform in disability policy occurred in the late 1960's and early 1970's. Traditional programs, policies, and assumptions regarding disabled people were attacked through the courts and legislatures. Advocates brought due process and equal protection challenges to the dehumanizing conditions in segregated institutions and sheltered schools. Supportive members of Congress passed landmark legislation to extend civil rights guarantees to disabled people. In short, disabled people began to be seen as a class of disenfranchised people denied basic civil liberties and social access.

Congressional reform occurred at a rapid pace. Integration and equality of opportunity mandates were enacted to provide access to public buildings and transportation.[17] The Rehabilitation Act of 1973 was passed, not only strengthening the commitment of the federal/state vocational rehabilitation system to address the needs of the severely disabled persons,[18] but also containing several policies with even broader implications. Section 504 of the Act defined the key national mandate prohibiting discrimination in employment,

education, and health and social services against handicapped individuals by recipients of federal assistance, in language identical to that used in the Civil Rights Act of 1964, and later in the Education Amendments of 1972 applying the same federal guarantee to women.19 Title V further mandated the creation of a federal board to coordinate and ensure access to public buildings and public transportation20 and prohibited discrimination in employment by requiring affirmative action by federal agencies21 and federal contractors.22

Through passage of the Education for All Handicapped Children Act, Congress mandated an end to separate and unequal educational opportunities. It required that "to the maximum extent appropriate, handicapped children (shall be) guaranteed a free, appropriate public education...and (shall be) educated with children who are not handicapped..."23 Finally, it passed legislation containing a bill of rights for persons with developmental disabilities, with the primary goal of providing services that would further the individual's potential to become a participating member of the community.24

The Congressional reforms of the 1970's took aim at the roots of historical prejudice and stereotypes that had isolated disabled people from organized society as an inferior caste. A clear summary of the overall intent of these reforms was stated in 1974:

> The Congress finds that...it is essential...to assure that all individuals with handicaps are able to live their lives independently and with dignity, and that the complete integration of all individuals with handicaps into normal community living, working and service patterns be held as the final objective.25

The passage of federal legislation, however, is not sufficient within the American political system to realize the reforms which impact on the lives of the constituency for which the legislation is intended. Adequate methods of implementation and enforcement must be defined, and these, in turn, must be reinforced by a broad base of support at the community level.

B. Disabled Persons: A Political Force

In April 1977, an event occurred which illustrated this process in relation to the development of disability policy. Demonstrations by disabled people

occurred throughout the country to protest the failure of HEW Secretary Joseph Califano to sign regulations implementing Section 504 of the Rehabilitation Act of 1973.

In the four years since the enactment of Section 504 in 1973, a set of compromise regulations had emerged from the evaluation of over 30 hearings and over 1,200 written comments. In response to Secretary Califano's refusal to issue the regulations, demonstrations occurred throughout the United States. In San Francisco, disabled activists occupied the offices of the Department of Health, Education and Welfare for 28 days until the regulations were signed. Protest activities were also staged in other major cities—including Washington, D.C.--to bring public attention and political pressure to bear on the enactment of the Section 504 regulations. These demonstrations, for the first time, showed the nation and policymakers that the growing grassroots disability rights movement was a significant political force.

A notable presence at the San Francisco sit-in were a number of individuals from a new kind of disability organization which had appeared in Berkeley several years before. The Berkeley Center for Independent Living (CIL), since its establishment in 1972, had gained national attention both as an expression of the new activism among disabled people and as a translation of the ideology of independent living into a dynamic program integrating services with social action. The creation of this prototype Center had given the independent living movement credibility and momentum.

Berkeley had been founded by seven severely disabled persons, including former University of California students, who had participated in the University's Disabled Student Program. (From that perspective) They had come to question the assumption dominant in rehabilitation thinking at least since the establishment of the disabled student program at the University of Illinois at Champaign/Urbana in 1950: that higher education was the "royal road" to social integration and personal independence for severely disabled persons. While it was recognized that gaining access to universities and colleges had been an essential innovation and one which needed to be expanded through application of the Section 504 mandate of physical and program accessibility, higher education

was now seen as just one point of access to independence.

The significance of the strategy embodied in the Berkeley model was that it not only had a flexible and individualized sense of the service needs of severely disabled people, it also took into consideration that individuals live within a physical, social, and economic environment which must be modified in significant ways to make independent living possible. It rejected residential programs as inherently paternalistic and debilitating and extended this critique to other social service practices which continue the dependency of the "client" constituency. Berkeley combined services and advocacy in the most straightforward and logical way: the Center itself was controlled and largely staffed by disabled people and designed to serve their needs as they saw them.

An example of what disabled people could achieve if given a meaningful opportunity, the Berkeley Center became a symbol of hope and dignity as well as a model for efforts in other communities. Its profound influence extended not only to disabled people throughout the United States, but also to many disability professionals,[26] Congress,[27] other important decisionmakers, and fostered the establishment of disabled run groups that focused upon policy and practices from the perspective of empowerment, integration and civil rights[28].

C. <u>State Funding of Independent Living: Proliferation of Forms</u>

In the mid-1970's, several state rehabilitation agencies (California, Michigan, and Massachusetts), influenced by the success of the Berkeley Center and anticipating the eventual enactment of federal independent living mandates, began experimenting with state discretionary funds (Innovation and Expansion Grants) to create a variety of programs described as independent living programs. For example, in 1974, the Boston Center for Independent Living—the first of five programs funded in that state through the grants—began providing transitional/residential programs and related support services. Independent living programs also formed in Houston, Ann Arbor, and numerous other cities in the early and mid-1970's.

As programs proliferated and assumed a variety of forms, the question of what it meant to be an independent living program was raised. The two most

significant dimensions of the emerging controversy were the distinctions between 1) "residential/transitional" vs. "community oriented" services and 2) "disabled control" vs. "disabled participation" in the organizations. While both issues remain significant, the latter was particularly prominent among the concerns discussed at the conference.

Independent living programs of the 1970's were not the only organizational forms which this activism generated. Coalitions, many under the sponsorship of or in conjunction with independent living programs, formed to press special issues as well as broad social policy affecting all disabled people, through programs in community education, organizing, research, and advocacy.

These independent living programs and advocacy groups are unique for several reasons. First, they cut across traditional medical/ charity distinctions to work with coalitions of people with different disabilities. Second, the new organizations were formed by disabled people living in the community who took on leadership roles to develop and run programs that met their needs.

From the very beginning, they differed from traditional social service programs which served disabled people in that they were designed to provide support to disabled persons from birth to death and were not "closure-oriented" in a traditional casework mode. Most started as coalitions of physically disabled and blind persons, and have painstakingly expanded these coalitions to include all disabilities in the community. Finally, these early programs started without the assistance of targeted federal money and have been maintained without this assistance.

D. Independent Living: A Federal Policy

Government funding of programs brought very different ideas about independent living. The differences stem from viewing it professionally as an innovation in rehabilitation methodology or as an expansion of the role of the state/federal vocational rehabilitation system. The impact of this professional point of view increased dramatically the tension emerging within the independent living movement with the advent of specific federal funding for independent

living services.

In 1978, Congress authorized support for independent living programs for the first time.29 The Rehabilitation Act of 1973 was amended to add Title VII, Comprehensive Services for Independent Living.30 As expressed in the legislation, Title VII was intended to assist in the development of community based service centers to provide housing referral, transportation, attendant care, and peer counseling and other services. The goal was to facilitate the integration of severely disabled adults into the mainstream of community, social, and economic life—i.e., to decrease their dependence and increase their self-determination and ability to be productive and contributing members of society.

Title VII established a basic change in federal disability policy, and in doing so reflected the growing influence of the community based independent living movement through specific legislation drawing on program experience of the early centers.31

Title VII has resulted in a marked increased in the number of independent living centers throughout the United States.32 For this reason alone, it has been of great benefit to disabled people in expanding needed services. However, the inclusion of independent living under the federal-state rehabilitation system has created conflicts both in the professional rehabilitation system and in the independent living movement. This results in part from a basic disagreement between professionals and "consumers" over the goal and intent of independent living programs.

Independent living was originally seen by rehabilitation professionals as an alternative form of services for disabled individuals for whom employment was not a feasible objective. Thus, for professionals the goal of independent living was provision of services that would permit certain disabled persons to live in a community short of being gainfully employed. Although this view is not shared by disabled advocates, many rehabilitation professionals retain this view and see independent living as a service form that competes with rehabilitation: As independent living programs grow, these professionals see them as

having potential to undermine the specific closure-oriented goal of gainful employment.33

From the point of view of grassroots independent living program directors, independent living encompasses employment. The goals are not competing, and employment is one of the ways an individual can achieve independence. Further, independent living is viewed by disabled leaders as a process which may require continued provision of a particular service in order to maintain independence.34 The traditional rehabilitation service system, however, assumes a termination point in the provision of services, i.e., the individual is employed, and the rehabilitation goal is achieved.

This policy conflict between vocational rehabilitation professionals and the community based independent living movement has major significance. First, on the federal level, currently funded independent living centers supported by Title VII cannot expect to depend on federal monies forever for existing programs. This demonstration program assumption has the effect of putting pressure on programs to conform to traditional service delivery norms. Second, federal Title VII funding of independent living programs is generally administered through the state rehabilitation agency. To the degree the state agency fears the independent living concept, misunderstands the leadership development role, or has been involved in conflict with independent living programs in their community advocacy role, there is an obvious danger of reducing the effectiveness of the community based independent living model through the imposition of rehabilitation service provision regulations35 and traditional accountability measures.36

Third, the federalization of independent living under the rehabilitation system has created tension in the independent living movement. The use of the concept "independent living" under federal legislation and the application of the concept to a wide range of program models which are not run and directed by disabled people and do not include community advocacy have created major political issues for community based programs. Can independent living be a mere

provision of services without undermining the overall goal of empowerment and advocacy? What is the value of federal funding if it creates another form of dependency and the loss of community control?

The policy conflict involved in the needs of state agencies for administrative standards versus the need of programs for flexibility to meet individual service needs has been the subject of conferences, professional papers, and policy reports,[37] many involving disabled people. The Independent Living Leadership Strategy Conference and report is the first attempt by disabled leaders and independent living program directors to look at these conflicts and needs from a grassroots perspective and to propose solutions that will assist the community based movement and enhance the rights of disabled people.

IV. Maintaining Independence: Operational Issues Confronting the Community Based Independent Living Movement

The community based independent living movement is facing a crisis. The crisis has been brought on by the rapid increase in the number of individual programs, the rapid growth within programs, and growth in the population that wants, needs, and demands to be served. The present situation has been exacerbated by reduced economic resources, public indifference, and the lack of networks and support mechanisms for independent living programs.

This crisis is not one of confidence or of a lack of belief in the goals of the independent living movement by disabled persons. Rather, it is a period in the evolution of the disabled-run independent living programs that requires evaluation and planning. The East Lansing Conference, from which this report comes, presented a unique opportunity for disabled leaders to outline the problems that must be confronted for continued growth, and develop options and strategies to assure that independent living programs and the disability rights movement can continue to work toward the social, political, and economic independence for all disabled people.

The operational issues Conference participants identified can be divided into five categories:

- Funding and Funding Development
- Leadership Development and Direction
- Organizational Development and Management
- Service Delivery and Community Needs
- Public Relations, Education, and Community Support

A. Funding and Funding Development

The most critical issue facing disabled-run independent living programs is the lack of a reliable base of continued and adequate funding. An estimated 80 to 90 percent of independent living program funds are received from the government.38 These are primarily grants and contracts from state rehabilitation agencies and federal Title VII funds provided through the state agencies.39

Government funds have resulted in a rapid increase in the number of programs that provide independent living services40, and are of great benefit to disabled people nationally. However, the heavy reliance on this single source of funds has created a series of problems for the community based independent living movement.

Government funds are not, as a general rule, a reliable source of long-term support.41 This factor undermines the stability of the movement and of specific programs and services. Funds provided by state rehabilitation agencies are in the form of grants and contracts for provision of services. Generally, they are discretionary funds of the state rehabilitation agency and are subject to budget restrictions and revisions.

The other major source of federal funding is that available from the state agencies to assist in establishing centers for independent living.42 Title VII has five parts, of which only one, Part B, has received appropriations from Congress.43 Part B appropriations began at $2 million in fiscal year 1979 and grew to $18 million in fiscal year 1982.

In the first year of funding under Part B, ten states were awarded grants of $200,000 to develop and establish centers. These grants were for a

three-year cycle, with applications for continued funding required each year. In the second year, the original ten states were refunded and an additional 25 states were eligible to apply. In the third year, the original ten received their last year of funding, the second group was refunded for their second year, and a third group was funded, bringing the number of states and programs receiving Title VII money to 35 and 135 respectively.

The fourth year presents a major problem for the federally funded centers. Part A was designed to provide funds that, after the initial three year start-up cycle, would be available for provision of direct services. The state agencies were to receive funds for purchase of independent living services from existing centers. Part A, however, has never been funded and is not expected to be in the near future. In addition, for the majority of programs, state and local government funds and private funds have not made up the difference. Thus, the cycle of funding new centers continues, and existing centers are being defunded or must compete with new programs for reduced levels of funding.

All of the foregoing raises an additional point regarding the impact of federal funding. There has never been an effort to think through the long-term purposes of federal resources in independent living—certainly none which involved the disabled community and resulted in a consensus on purpose and direction. Without a comprehensive plan, one can expect mixed messages on funding stability, funded agents, and goals and purposes.

The inability of community based centers to find sufficient alternative sources of funding results from numerous factors. First, there is severe competition at the local level for resources to replace those lost by federal reductions in all social service programs. In this regard, disabled-run centers are at a disadvantage as the new kid on the block looking for funding from other groups' funding sources.

Second, there is a lack of awareness and understanding on the part of local government and private funders regarding the unique service/leadership role of the independent living programs. An attitude generally exists that the services duplicate those of existing social service agencies or that disabled people are

presently provided for by existing federal and state programs and by private charities—so much are disabled persons seen as non-active persons to be dealt with by charity or welfare programs.

The majority of community based centers have been in existence for less than four years. To implement and establish a new organization as well as carry out the community education and outreach necessary for long-term survival is a major undertaking for any program. However, in the case of the disabled-run community based centers, this is made more difficult because federal start-up money is provided for only three years. During this time, the organizational leadership and Board are, by definition, developing new skills and potential. And they are undertaking a venture in social services/leadership development that is revolutionary in disability policy.

The older community based centers that were established prior to the Title VII legislation have a slightly broader funding base and, in a few cases, are established as an important and unique part of their communities. However, the passage of time does not solve the funding issue.

In developing and operating the centers, the Conference participants identified a series of issues that must be addressed to ensure a secure funding base for long-term survival for independent living specifically and the disability rights movement generally.

1. Images of Disabled People in the Fundraising World

The independent living/disability rights movement is struggling to overcome traditional images of dependency. Changing these public attitudes is the major task of the movement and is a major obstacle in obtaining support from funders.

Traditional charities, utilizing images of "crippled" children and helpless adults, have fostered the portrayal of the charity model in the funding world. Government programs, in the great majority, were developed to take care of the "deserving poor" on the theory there

was no meaningful future for most disabled people.

This pattern of charity and paternalism in traditional fundraising betrays the philosophy and goals of the independent living/disability rights movement.44 It presents a major obstacle that can be overcome only by educating funders and increasing the involvement of disabled people in the fundraising world through positions on Boards and Advisory Boards and in the direct process of fundraising. Only through this process can disabled leaders reshape the priorities of funders away from programs that continue to support dependency and charity to programs that support the integration of disabled people into the social and economic mainstream.

2. Education in Fundraising Skills

Directors of nonprofit organizations all recognize that fundraising is part skill, part art, and part contacts. They also recognize that fundraising is, by necessity, a full-time occupation and a process that requires long-term planning.

Though all community based independent living centers have fundraising mechanisms, fundraising is generally one of the responsibilities assumed by the Director and not through an established development office. The Conference participants recognized a need for training in fundraising skills and related long-term planning.

3. Board of Directors: Fundraising Resource or Community Responsive

Traditional nonprofit organizations develop Boards of Directors that can assist in the fundraising process. The Board can be an important resource, and, in many cases, a willingness to assist in fundraising is a requirement for Board membership.

Community based independent living programs vary greatly in their Board make-up. Most programs, however, attempt to ensure the

majority of members are disabled people to ensure the organization is responsive to community needs.

In many cases the disabled person serving as a board member will not have the broad background and experience necessary to assist in fundraising. This includes contacts, skills and resources a non-disabled person selected as a board member is more likely to have developed as a participating member of society. Thus the desire to have a community responsive Board made up of disabled leaders may be inconsistent with the generally assumed role of fundraiser that board members undertake.

The Conference participants recognized a need for education in Board development, utilization of Board members, and development and utilization of Development Advisory Boards.

4. Economic Development

Economically disadvantaged groups have traditionally undertaken community based business ventures to provide meaningful employment opportunities, to develop leadership and business skills, and to provide a secondary funding source for community based programs.

A number of community based independent living programs have developed business enterprises related to their community service needs. Most notably, businesses have been developed in the areas of wheelchair sales and repair, the sale of other disability aids, and van and motor vehicle modification for disabled drivers.

Other groups which have developed profit-making businesses have not been able to fully sustain all their programs and costs from this source alone. Clearly, there will always be a need for other sources of funding, particularly from government and foundation sources. The Conference participants recognized that there must be further research and development in this area.

B. Leadership Development and Direction

The original centers grew in an organic fashion: a leader or group of leaders saw a need and developed mechanisms and coordination to meet that need. The leadership group generally had to undertake fundraising, organizational and program development, and related activities involved in creating and directing an alternative social service/leadership development organization. Further, the leadership group was acting alone, outside the mainstream, and had few, if any, outside resources or sources of support.

Federal involvement in independent living has, to some extent, assisted in the development process of the centers. But, this involvement has not greatly assisted disabled leaders in developing necessary leadership skills. Rather, it has imposed traditional structures and management techniques upon a non-traditional service/leadership development model.45

The resulting conflicts between the rehabilitation professionals and the disabled leadership,46 and the continued pressure to conform to traditional service provision models and accountability measures have made disabled leaders recognize that they must look to developing their own resource bases, support mechanisms, and power structures in order to maintain the integrity of the community based independent living model.

The push to maintain the integrity of the independent living movement is derived from the recognition that to achieve self-reliance and the right to shape their own destinies, disabled people must be leaders in the process. This recognition is not a denial of the need to develop professional organizations that meet high standards. Rather, it is focused on the issue of who develops the standards, professional criteria, and evaluation tools, and whether or not these criteria and standards are appropriate to the goals of a community based independent living program.

Leadership development is a clearly recognized need that must be viewed from a number of levels. At each level, the goal is to increase the

self-determination and self-reliance of the individual and further the integration of disabled people into the broader social and economic mainstream.

1. **The Role of the Center in the Community**

Each Center must, by definition, be an agency oriented to leadership development. As part of its role to be responsive to the community and meet community needs,47 the Center must continually undertake outreach and education activities to assist disabled individuals who want increased options and access to the community. The Center must also assist in skills development for the Center's personnel both to meet their own needs and to assist disabled individuals in achieving employment and education options in the broader community.

The major responsibility for ensuring that the Center is providing the necessary services and engaging in appropriate advocacy efforts for the community rests with the Executive Director and the Board of Directors.

The Conference participants recognized the need for training and support in leadership development and in organizational planning for staff and Boards of independent living programs. While disabled people must be in top management positions and in majority numbers on the Board, many disabled people are new to the experience of management or serving on a Board of Directors and unsure of the responsibilities and conflicts inherent in these roles.

2. **The Role of the Individual Center in Relation to Other Centers**

There is a sense of isolation among the leaders of independent living programs, because they operate alone, without the reinforcement of a larger group with similar goals. The lack of communication among programs also underutilizes the skills, knowledge, and resources available within the network.

The Conference participants recognized the need for a strengthened network of community based independent living programs to provide support, resources, and information sharing. Further, the expressed need went beyond networking among the Centers, to the need for mechanisms to educate the general public and decisionmakers on the role of independent living centers and facilitate involvement of programs in the larger decisionmaking and policy development process.

3. The Role of the Independent Living Movement in the Disability Rights Movement

The independent living movement and disability rights movement are united by the same philosophical values and the same goals of integration into the social, political, educational, and economic mainstream. Disability rights organizations operating on both the state and the federal levels have increased in number over the last five years. They focus on broader policy issues and pursue their goals through programs in education, research, advocacy, networking, and leadership development[48]. Their leadership includes an increasing number of disabled people from leadership positions with independent living programs. In many cases, the disability rights organization may be part of an independent living program or working in coalition with one or more centers. These organizations promote disabled leadership and involvement in the decisionmaking process and tend to be run by and for disabled people.

Disability rights organizations began because, like independent living programs, there was a recognized need. The leadership became aware that as independent living programs assisted an increasing number of disabled people to pursue lives with greater freedom of choice, true integration would occur only by increasing their involvement in the broader social and political arena. The question became: What is the value of achieving self-reliance and independent living skills if one cannot utilize them to achieve full potential and foster change in the social, educational, and economic mainstream?

From the point of view of disability rights advocates at the state and national levels, the process of fostering broad change in the social and political system has value only if there are increasing numbers of disabled people wanting and able to lead productive, fully integrated lives. It is clear, therefore, that the community based independent living programs play a central role in the process of integration by acting as catalysts for change in local communities and in the individual lives of disabled people. They are a central part of a process of social and political change that is having greater impact each year.

The Conference participants recognized that the independent living movement is a key part of the process of social change necessary for integration. However, it was recognized that the dynamics of this key role is not well understood by individual centers and that greater communication, leadership development, planning, and linkage were necessary to ensure the movements pursue complementary goals and coordinate activities to ensure long-term social change and integration.

4. General Issues Related to Leadership Development and Direction

A series of general issues that affect leadership development and direction of the independent living and disability rights movement at all levels were raised at the Conference. These issues address the concern that as the movements mature, they must expand programs and activities to include disabled people outside the traditional core constituency49, and they must address the role of the non-disabled person.

Expansion of the Core Constituency

As with other social movements, the early leadership in the independent living/disability rights movement tended to be better

educated and from more stable socio-economic backgrounds. They tended to be young adult white males from a few specific disability groups: spinal cord injury, postpolio, cerebral palsy, muscular dystrophy, and multiple sclerosis.50 As the movements have matured, there has been increasing recognition that the constituency base and the leadership must expand to include: (1) greater proportions of racial and ethnic minorities and women; (2) a broader range of disability groups; (3) a broader age range of disabled people, including children and older persons; and (4) parents of disabled children.

• Racial and Ethnic Minorities and Women

It has been noted that there is a higher incidence of disability among racial and ethnic minorities, women, and persons who are poor.51 It is unclear whether the lower involvement of racial and ethnic groups in the independent living/disability rights movement is a product of the larger issue of sex and race discrimination; a product of differing family and cultural backgrounds relating to the treatment and expectations of disabled persons who are of different races or women; or a combination of both and other unknown factors. The Conference participants strongly believe work must be undertaken to include racial and ethnic minorities and women in programs and activities and in leadership positions.

• Expanding Involvement of Disability Groups

As with racial minorities and women, there is an understanding within the movement that both independent living and disability rights groups must expand their programs and activities to include disability groups outside the traditional core constituency. Policy changes in the last decade away from institutionalization and toward community based living have placed new pressures to expand programs and activities that will open society to participation of mentally retarded and mentally impaired persons, as well as increased

participation by deaf and blind persons.

The growth of the independent living centers has had major impact on deinstitutionalization. This factor is placing added pressure on independent living programs to develop service models and provide resources to serve and assist these additional disability groups. It is recognized that a failure to undertake these actions may result again in a split between the physically disabled and mentally disabled, in the duplication of many programs, or in an increased tendency to put resources into traditional residential programs rather than non-residential services and advocacy centers.

The Conference participants recognized work must be undertaken to include a wider range of disability groups in disabled-run, non-residential independent living programs and in the broader disability rights education and advocacy policy activities.

• Expanding the Age Range and Including Parents and Their Children

As noted, the early leadership of independent living programs tended to be young adults, with a marked absence of older persons and little focus on services for disabled children and youth.

From one point of view, this can be understood if one considers the evolution of the community based centers. They were designed by a constituency of disabled persons who were excluded by existing service patterns. They were individuals of an age and educational level who wanted to live outside a family setting and were not prepared to spend their adult lives in nursing homes and institutions.

There is a clear recognition that the incidence of disability increases with age and that the concepts and services provided by independent living programs are of value to older Americans. As a result, many community based programs serve older persons as a general part of their services. However, there has been little

involvement of older persons in leadership positions in either the independent living or the disability rights movement. This may change as the leadership of the movements grows older[52] and as the organizations representing and serving both populations work on issues affecting disabled and older persons.[53]

A second issue is involving children and parents in the movement to integrate disabled people into society. There has traditionally been a split between parents and disabled adults. In large part, this is in response to a view that parents have played a major part in maintaining dependency and paternalistic patterns of living. However, there is increasing recognition on the part of disabled adults that they must ensure the integraton of disabled children in education and service programs in order to promote system and value changes in the primary and secondary schools and in disabled and non-disabled children so that segregation and disenfrachisement of disabled people is not perpetuated. This integration is necessary to ensure that the concepts and philosophy of the independent living/disability rights movement become the norm for future disabled leaders.

Further, there is increasing recognition by parents that role models for their children must come from disabled adults. If disabled adults are self-reliant, living productive lives, and undertaking leadership positions, it offers greater hope for each disabled child's future.

Coalition work between parents and disabled adults has been most effective on issues involving section 504 and P.L. 94-142, which prohibit discrimination in education, social services, and employment.[54] However, there is increasing involvement by disabled leaders on the community level in schools and with parents groups undertaking advocacy and services activities.

The Conference participants believe disabled-run independent living

centers and disability rights groups must undertake and explore joint activities that will further integration and participation.

The Role of the Non-Disabled Person

A major issue that has become a focus of greater concern and debate over the last few years is the role of the non-disabled person in the independent living/disability rights movement.[55] It is similar to the tensions that existed in the civil rights movement on behalf racial minorities and women.[56]

It is an important issue in disability because of the history and numbers of traditional professions and programs that were dedicated to care for, help, and protect disabled people. The programs traditionally molded the life options and directed decisionmaking for the disabled person in education, rehabilitation, and related social services; employment, training, and opportunities; medical care; and recreation/leisure. Each program area fostered the problems disabled people face of dependency, segregated and sheltered care, and stereotyped job options. The charities fostered attitudes of pity and helplessness in order to raise funds for disabled people. In each area, the decisionmakers and providers have been and continue to be predominantly non-disabled.

Both the independent living and disability rights movement focus upon disabled people assuming control over their own lives and their increased involvement in the decisionmaking process. The role of non-disabled persons will continue to create controversy within the movement and with non-disabled professionals in both rehabilitation programs and related policy areas, and in the broader civil rights policy arena.

The Conference participants believe the issue must be addressed both within local community programs and in the broader movement. The participants recognize an increasing tendency to hire non-disabled

persons for leadership and management positions, thus weakening the leadership development role of the programs. This tendency is becoming more apparent as the centers are pressured by federal and state agencies to become more oriented toward traditional social services and less oriented toward advocacy. The long-term result of this pattern is the loss of the ability to serve as catalysts for community change and change in the lives of individual disabled people in the community.

For both the independent living and disability rights movement this is a major concern. The loss of leadership at the local level and the loss of mechanisms to develop new leaders weaken the movement's ability to achieve its goal of integration. Thus, the participants recognized that the issue must be addressed and must be confronted in a manner that is not merely separatist, but recognizes the necessity of working with and within the professional system to affect necessary change, and supports and fosters the ability of disabled people to direct their own lives and achieve increasing involvement in the decisionmaking and policy setting arenas.

C. Organizational Development and Management

As discussed above, the director of a community based independent living program is not only a community leader, but also the executive administrator of a non-profit corporation. Each of the Conference participants recognized a need for support, technical assistance, and training in administrative and management skills.

Legal and Corporate Issues: A large group of independent living programs do not have a corporate attorney representing them. In some cases, the management is not sure if and when such assistance is necessary. This is true because of cost: pro bono assistance is generally limited in use because it is free. Further, many of the potential problems confronting independent living programs are

unique to disability groups, and attorneys who are familiar with these issues and non-profit organizations are limited in number.

The issue areas range from adequate articles and by-laws to contracts and contractual liability, from potential tort liability in provision of services (e.g. attendant, wheelchair repair, transportation) to personnel policies.

The need can be addressed by development of guides to potential problem areas; individual technical assistance in general problem areas; and assistance in developing contacts among and support from the local private bar.

Board Development and Utilization: Outside the area of leadership development, training and support for directors in Board development and utilization of the Board in policy setting, planning, and fundraising are necessary. There is also an expressed need for training in the proper role of the Board in relation to their corporate responsibilities.

Organizational Planning: As a general rule, directors of the community based programs are too busy with day-to-day needs to plan the development of the center and inadequately prepared to undertake the task. A need expressed at the Conference was individual as well as network support and training in the skills and techniques of organizational development.

Personnel Management and Staff Development: Each participant of the Conference recognized a major need existed in the area of personnel management and staff development. The issues under personnel management included personnel policies and affirmative action, management skills, and development of adequate and appropriate job descriptions and pay rates. Other issues include staff recruitment, training, and reasonable accommodation to ensure a disabled person can undertake and carry out job duties. Staff

development includes training for individuals who have potential to assume greater responsibilities, the use of interns, and the use volunteers to develop individual skills through on-the-job training.

Fiscal Management: A major skill required of a non-profit director is in the area of financial management. The Conference participants recognized the necessity of maintaining proper fiscal records and procedures. Support and technical assistance is needed in order for directors to understand non-profit accounting principles, cashflow management, and to acquire or train for the skills and staffing needed to ensure the financial health of the corporation is maintained.

Evaluation and Program Accountability: The community based centers are faced with pressure to apply traditional evaluation and case management techniques as well as accountability systems to their services and advocacy programs.[57] However, it is recognized by disabled leaders and professionals that these tools are inappropriate to the independent living programs.[58] The debate will continue over the type of tools that are appropriate, but it is recognized that such techniques and standards are necessary for the future growth and development of the movement.

D. Service Delivery and Community Needs

The central focus in the development of the independent living programs has been the provision and coordination of services that would enable an excluded segment of the population to achieve independence. As programs increased in understanding and sophistication, it was recognized that advocacy was a key component to ensure community needs were met and individuals who received the services would continue to develop added skills, self-reliance, and the ability to move into the wider community.

The early programs developed to meet similiar goals but varied in the methods and techniques of service delivery and advocacy. Service delivery methods in a large urban area were not appropriate to rural areas. Differences

exist among urban areas according to the availability of public and/or private transportation. Differences exist in population served based on racial and cultural differences and disabilities. However, each program confronts certain common problems that must be addressed.

In addressing community needs, programs face the dual issue of increased demand for services and limited resources and delivery mechanisms. Within the last five years, the concept of independent living has expanded from its initial core constituency to a greater range of disability groups who desire access to the services of an individual center. At the same time, centers are facing limited resources and the need to establish priorities for service provision.

Further, in many communities, the existence of an independent living program is an excuse for other social services groups not to serve the individual and to refer him or her to the center. This occurs regardless of the nature of the problem; that is, it may be a legal or service need that has nothing to do with the disability, but because the person is disabled he or she is referred to the independent living program.

The Conference participants recognize the dual tensions facing each program. They recognize that the movement must communicate the need for their services and advocacy to the public and work to foster the development of resources and skills necessary to meeting the needs of all disabled people who desire the opportunity to live independently.

E. Public Relations, Education, and Community Support

An area of further concern raised by the Conference participants focuses on the relationships with organizations and agencies outside the disability area and the development of broad-based community support. Because the independent living programs are both service providers and advocates for the rights of disabled people in the community, their relationships with and ability to educate the broader community are necessary for their individual survival and the expansion and growth of the movement toward integration.

This area includes utilizing the media and public relations; developing relationships with groups providing services and advocacy to other disadvantaged groups; establishing contacts with and support from local and state officials; and establishing contacts with and support from corporations, banks, and other institutions within the community.

Conference participants recognize this need for their individual programs and utilize varied approaches to communicate and develop supportive relationships with the broader community. Specific programs often involve video or slide presentations, speeches and meetings with local business clubs (i.e. Rotary, Lions, Chamber of Commerce), participation in advisory boards, working in coalition with other community groups on common issues affecting programs or poor people generally, and meetings and education of decisionmakers in local, state, and federal government.

It was apparent that each program must develop its approach and related materials according to the specific program and the specific community. However, it was recognized that this need could be met equally well by dissemination and sharing of existing resources developed by individual centers; by technical assistance and training in media use, public relations, and related skills; and by technical assistance in resources and resource referral.

V. Achieving Independence: Future Options and Strategies

Independent living programs provide the grassroots representation, service delivery, and advocacy which assure disabled persons a method of affecting and determining their roles in the community and their rights to participate fully in all the benefits the larger society offers all of its members. In the decade since the initiation of independent living programs, their numbers have grown, external support has multiplied, the numbers of severely disabled persons assisted to become more fully independent in the community have increased substantially, and their impact--both directly and indirectly--within their immediate communities and at the state and national levels has resulted in major attitudinal and policy changes.

Like other non-profit organizations, independent living programs have developed skilled community leaders, managers, and program administrators, provided on the job training and developed innovative and effective methods of service. Unlike most nonprofit agencies, however, independent living programs are at the core of the political and civil rights movement of the population they serve. Their continued growth and survival, therefore, will play a determining role in the success of the disability rights movement.

As pointed out above, the initiation and the growth of federal funding has been a mixed blessing. Distribution of funds on a broad scale and lack of agreement on the purpose and goals of independent living, combined with a perceived lack of leadership credentials in the disability community, have fostered the growth of programs which are only nominally controlled by disabled persons. Lack of understanding of community based programs, a short start-up period, and the recent recession set existing programs competing with new ones in a time which has proved tumultuous for even long-established nonprofit organizations. If federal funding were only a part of independent living development sources, the pressure would not be so great. The case, however, is that only a few programs have other major sources of funding they can rely on, and next to none have sources which provide the kind of financial latitude or flexibility needed over the long term.

Alternative sources of funding, however, are not the only barriers to successful program development. Independent living programs, as with the broader disability rights movement, are young in age and in breadth of experience. Several points can be drawn from this statement. First, leadership and management of these programs have developed on the front lines - hard experience gained through meeting service delivery needs or battling a recalcitrant agency to make changes in policy or service guidelines. As stated before, most program leadership developed as a result of pursuing a particular service goal, e.g., availability or accessibility of noninstitutional housing, pursuit of attendant care support, back-up services for disabled students, or undertaking a needs assessment to encourage the development of service support systems for adults in rural areas. As a result, many leaders have been caught

on the edge of change—without the chance to reflect on leadership skills, leadership development, and planning. Virtually none of the directors and few of those who are now joining the ranks of former directors had exposure to the breadth of demands all faced in the last several years.

At the current time, little exists to provide directors the support and back-up needed to undertake agency leadership in such turbulent times. In terms of seeking assistance from their peers, getting expert technical assistance from others who understand their program goals, or formulating cross-program policy and resources which will serve all programs with similar goals, they are at a severe disadvantage. This is not to say that technical resources do not exist. What is not in place are methods to access these resources, either through networking or through sufficient communications and flexible resources to make the assistance available.

A third point, however, must be made about the youthfulness of programs. Independent living programs have been the leadership corps for the massive disability policy change which has taken place over the last decade. As leadership changes in the programs there are few options available in the disability rights community for those who have developed management, political, and advocacy skills, and are leaving the independent living programs. The broader disability rights movement has few resources to further make use of these skilled individuals.

At the same time, little exists as an infrastructure to assist programs with policy development, collection and dissemination of information, and linkages of the independent living programs to other disability organizations and civil rights and advocacy groups. Given funding, a clear match could be made between these developed skills and growing needs for expert policy development. What follows is a discussion of each of the major areas of action recommended by the participants of the Independent Living Leadership Strategies Conference. These recommendations address five major needs: (1) Support and Technical Assistance in Operations and Management, (2) Development of Strategies for Networking and Communications, (3) Leadership Development and Training, (4) Research and Policy Development in Independent Living, and (5)

Long-Term Planning.

A. Support and Technical Assistance in Operation and Management

As highlighted above, much of the initial conference discussion centered on current day-to-day operational problems. While technical expertise exists to assist programs, most directors focused on the fact that they often had neither the time nor the resources to attend to long-term planning and management solutions. What is needed is a technical assistance or support capacity which might be organized on a regional or a state basis which could assist program directors:

- In identifying persons in the independent living movement who have worked on similar day-to-day problems;
- By providing on-site training and planning assistance to help them solve current problems; and
- By identifying particular issues which are causing problems and developing solutions for independent living programs.

At the center of this need, however, is basic assistance, which could be provided fairly simply. As noted, most independent living program staff have had limited experience in organizational management. Packages of materials which respond to agency needs would save many from "reinventing the wheel".

These packages would include: (1) a simplified accounting package which deals with funds management, development of an indirect rate, and handling multiple sources of funds; (2) a funding source document which organized service support by program; (3) job descriptions for most basic positions common across independent living programs; (4) reporting requirements for federal money; (5) pay scales; (6) employee grievance procedures or unionization questions; (7) a personnel policies guide; (8) job recruitment and search procedures; (9) selection and functioning of a board of directors as well as board relations and training; (10) designing services, balancing services and advocacy, and roles of peer counselors in counseling and advocacy; (11) structuring benefit packages — particularly insurance variations; and (12) legal issues affecting the organization's overall corporate integrity.

While these materials would not be needed by all programs, their

availability would save much time and effort. Access to expert resources recommended by other independent living programs would take programs a second step.

Such a technical assistance resource system would cover the range of short-term problems identified (e.g., funds management and funding development; personnel development and management; management planning for service development and advocacy; board selection and relations; and community relations). While it might begin as an externally-based system, the capabilities of technology and existing expertise within programs could allow the development of shared resources across programs through the development of a computer-based system.

B. Need for Network Capability and Cross-Program Communications

The comments above demonstrate the need for a networking and communications capability across programs which cannot be satisfied by occasional contact or discussion at conferences or in regional group meetings. Clearly, coalitions at the state level begin to satisfy this need, although the need to share information on common issues and problems at the national level, particularly for program leadership, is critical.

This need encompasses all areas: day-to-day management problems, common accounting and reporting systems, for funding source information, legislative development at the local, state and national levels, for recruitment and job searching, innovative methods and adaptations, representation of independent living programs at the national and state levels, on training programs and leadership development options. Clearly, the fact that most of the directors present at the Conference had not had a chance to meet previously on long-term planning is apt testimony to this point. At present, this need is satisfied only partially by: occasional travel and meetings through federal auspices, a newsletter put out by ILRU and technical assistance, occasional reporting through regional offices, updates from national organizations (most of which deal with specialized information) and through beginning efforts of the emerging National Coalition of Independent Living Programs.

As identified by Conference participants, this need can be described at three levels: the sharing of information across sites which might be used by programs at will, networking and communication which requires discussion and decisionmaking, and joint activity which will benefit all programs but could not be done by any single site. Specific activities are as follows:

Level 1: Sharing of Information Across Sites/Picked Up at Will

- **The creation and maintenance of a National Job Bank** - identification of disabled persons and their skills, together with a separate posting for available positions.

- **Sharing of Information on and Updating Individual Independent Living Programs** - reporting on recent activities of community based independent living programs, including extension of service to new client populations, successful community advocacy efforts, and changes in law and guidelines.

- **Reporting of Developments in the Field** - identification and reporting of community coalitions, new applications of technology, and new methods of fundraising.

- **Referral to Expert Resources** - identification and site evaluation by programs of consultants used, availability of expert resource through newly funded projects, including utilization of former Directors as experts.

Level 2: Networking and Communications Which Require Discussion and Decisionmaking by Independent Living Programs

This activity requires direct involvement of independent living program directors and assumes the representation of all programs through an organizational entity, such as the National Coalition of Independent Living Programs. Primary elements include the following:

- **Consensus Building on Priorities and Standard Setting** -- includes policy development and definition of standards for community based independent living programs, such as: the role of non-disabled in independent living programs, the range, philosophy, and delivery of services, the role of programs in community, the relationship between programs and other community institutions, and the role of the director as a disabled leader in the community.

- **Development and Representation of Needs to the Public** -- primary publics include the national media, foundation and corporate funding sources, policymakers—in Congress, the Executive Branch and the Courts—the general public, and professional groups. Included here are both representation and the creation of support for community based programs, such as public relations campaigns, political response capacity, and outreach to funding sources.

- **Development of and Assistance to New Programs** --identification of areas needing programs and identification, and recruitment and training of potential directors.

Level 3: Joint Activity on Behalf of Independent Living Programs

Beyond assistance to programs to carry on current activities, steps must be taken to develop the capacity for programs to sustain themselves in the future and to move away from primary dependence on governmental funding. Although these are long-term strategies, planning and development activities must be undertaken by the independent living programs jointly or by an organization or entity representing the community based programs as a whole. Two primary needs were identified at the Conference.

- **Consortium Funding** - the creation of an entity of program interaction which would not necessarily carry out programmatic

activities outside resource development, fundraising and distribution of funds to community based programs.

- **Development of Alternate Methods for Program Support** - the primary option discussed under this heading was the development of program-owned business ventures, although other options such as partnerships with other organizations or collaborative ventures, other fee for service activities, and shared resource plans (health benefits packages, use of loaned executives) are possible.

C. Leadership Development and Training

Critical to the development of community based independent living programs is the recruitment and training of disabled persons to direct and staff existing programs, start new programs, and take on broader leadership roles in the community and in support of the goals of the independent living movement. At the present time, most training takes place on the "front line" through experience, and to some extent through transfer to programs in other communities. Because of the youth of the programs, disabled staff have not had access to the many alternate forms of specialized training and experiences which allow the development and maturity of leadership skills. More formal training programs need to be developed which can assure programs of a cadre of capable staff to carryout the broad range of responsibilities at the program level, and will allow disabled persons to expand areas of current responsiblities.

The pattern of emergence of disabled community leaders has brought forward persons immersed in location-specific problems. Little time has been available to compare individual circumstances to other areas, or to sort out skills and techniques which can be useful in broader areas. This grassroots training has been critically important to producing self-trained and capable persons with a shared experience and unique knowledge. As expressed by the Conference participants, what is lacking is that broader set of experiences, relationships, and exposures to enable them to hone their skills, broaden their capabilities, and put to work in other ways the knowledge gained in solving their own community problems. What is needed is a leadership development and training

plan encompassing the following objectives:

1. **Training of Existing Program Directors and Staff in:**
   - Fiscal and program management
   - Public and community relations
   - Legislative development and advocacy
   - Leadership and staff development skills
   - Fund development and fundraising

2. **Recruitment and Training of New Leaders and Staff for Programs:**
   - Outreach to minority and underserved disability community
   - Training and outreach activities for development, recruitment and program start-up of community based independent living programs

3. **Leadership Skill Enhancement for Existing Directors:**
   - Training in public management and public policy
   - Development of internship and Fellowship opportunities to enhance public policy and research and management skills, with emphasis on state and national levels
   - Development of programs to allow short-term replacement of staff for staff development programs

4. Leadership Programs for Directors and other Disabled Leaders to Develop Capabilities for Linkage and Leadership Activities in Major Generalist Policymaking Positions:

- Internships and Fellowships for ILP leadership with organizations involved in broader disability rights arena

- Internships and Fellowships through major institutions to enhance credentials of disabled leaders

- Specific leadership skill programs to develop understanding of public policy and management and translate the skills gained to other arenas

D. Research, Policy Development, and Long-Term Planning

As long as community based independent living programs are continually pressed by primary issues of program management, crisis advocacy and stabilization of a funding base, there can be no focus on the major policy and planning problems that continue to plague individual programs. This creates two problems--the failure to solve issues which may prove to be their downfall, and the cooptation of community based programs besieged by demands for accountability from external sources. The fourth major area of focus for the Conference is the need to develop a capacity internal to the disability rights movement to carryout research, identify and develop policy options, and conduct long-term planning.

For example, this capacity would include:

1. Policy Research and Development Activities Which Expand and Reinforce the Process of Integration

- Attendant care programs on the state and national level
- Independent living models in rural areas
- Independent living models for mentally retarded individuals
- Employment disincentives in support programs

2. **Research and Long-Term Planning for Independent Living Programs**

- Development of a comprehensive plan for use of federal resources in independent living

- Development of an effective evaluation method for community based independent living programs

- Development of standards for community based independent living programs

- Development of economic development options for community based programs

- Collection of data on programs, their communities and their impact

- Impact of technology on independent living

E. Long-Term Planning/Linkages to the Disability Rights Movement

Finally, this report ends where the initial project began: with the need for concerted efforts at long-term planning to determine where the community based independent living movement and the broader disability rights movement should be in ten years.

Conference participants addressed the need to broaden long-term planning to focus on the political environment, addressed linkages between community based independent living programs and the disability rights movement, and linkages to other groups representing disenfranchised populations. Specific issues which must be addressed in these areas are the following:

- Development of consensus on a plan and component steps to assure the disability community as a whole achieves full participation in society

- Identification of the specific linkages which must be forged with other groups to improve the probability of success in meeting this goal (e.g., what can be learned from the history of other groups in achieving participation and access to economic and political equality)

- Identification of specific activities to develop a political power base within the disabled community to achieve full community participation and integration into the social, political, and economic system

- Determination and communication of the steps the disabled community must pursue in the area of civil rights policy in federal and state government—including the courts and legislatures—to ensure broader options of integration and choice

- Examination of the impact that changes in technology, economic development, and political and demographic forces will have on the disability rights movement

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Appendix A.

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2 See List of Participants - Appendix B.

3 DeJong, G. The Movement For Independent Living: Origins, Ideology: and Implications for Disability Research, Paper presented at the Annual Meetings of the American Congress of Rehabilitation Medicine, New Orleans, LA, November 17, 1978 at 33. (hereinafter DeJong, The Movement).

4 E.g. Frieden, Lex, Independent Living Models, Rehabilitation Literature, Vol. 41, No. 7-8, July-August 1980, at 170. (hereinafter Frieden).

5 DeJong, The Movement, supra note 3 at 34.

6 See DeJong, Independent Living: From Social Movement to Analytic Paradigm, Archives of Physical Medicine and Rehabilitation, Vol. 60, October 1979, 435-446. (hereinafter DeJong, Independent Living) See also Hahn, H., Disability and Rehabilitation Policy: Is Paternalistic Neglect Really Benign? Public Administration Review, July/August 1980 at 385-389.

7 See Frieden, supra note 4.

8 See Appendix C, Philosophy.

9 See Frieden, supra note 4 at 170.

10 DeJong, G., The Historical and Current Reality of Independent Living: Implications for Administrative Planning, Policy: Planning and Development in Independent Living, University Center for International Rehabilitation, Michigan State University, June 1980. (hereinafter DeJong, Policy at 170). See also DeJong, The Movement, supra note 3.

11 See Frieden, supra note 4; DeJong, Independent Living, supra note 6; Hahn, supra note 6.

12 See Frieden, supra note 4 at 170, 171.

13 Id.

14 Id.

15 See e.g., Funk, R. Law Reform in Disability Rights: Articles and Concept Papers. Volume I, A-1, A-50. Disability Rights Education & Defense Fund, November 1981; DeJong, The Movement supra note 3.

16 DeJong, The Movement, supra note 3 at 20.

17 Architectural Barriers Act of 1968, 42 U.S.C. §4151 et. seq.; Urban Mass Transportation Act of 1964, as amended, 49 U.S.C. §1612; Federal Aid Highway Act of 1973, 29 U.S.C. 142.

18 P.L. 93-112; P.L. 93-602, 29 U.S.C. §702, (Supp. II 1978).

19 29 U.S.C. §794, (Supp. II 1978).

20 29 U.S.C. §792, (Supp. II 1978).

21 29 U.S.C. §791, (Supp. II 1978).

22 29 U.S.C. §793, (Supp. II 1978).

23 The Education Acts of 1974 and 1975, 20 U.S.C. §1401, et.seq.

24 Developmentally Disabled Assistance and Bill of Rights Act of 1975, 42 U.S.C. §6001 et.seq.

25 White House Conference on Handicapped Individuals Act, 29 U.S.C. §70 in (December 7, 1974).

26 See DeJong, Independent Living, supra note 6, 435-446.

27 See "Oversight Hearings on the Rehabilitation Act of 1973" before Subcommittee on Select Education of the House Committee on Education & Labor, January 5, 1979, at the Center for Independent Living, Berkeley, CA.

28 See discussion infra at (IV)(B)(3) and footnote 48.

29 Federal initiatives in independent living had been attempted as early as 1959. Consumer advocates and rehabilitation professionals, recognizing that traditional rehabilitation services were not being made available to large numbers of severely disabled people because they were not deemed "employable," persuaded Congressional supporters to introduce independent living legislation in 1959, 1961, and 1973. In each instance, the independent living legislation was not enacted. DeJong, Independent Living, supra note 6 at 437. See also Burton, L. Law Reform in Disability Rights: Articles and Concept Papers (Vol. 1, B-11, B-13, (November, 1981).

30 P.L. 95-602, §122(a)(b)(c); 29 U.S.C. §706, (7) (Supp. II 1980).

31 See e.g., DeJong, Independent Living, supra note 6.; "Oversight Hearings," supra note 27.

32 By fiscal year 1982, 135 centers for independent living were being funded under Title VII; Testimony by George A. Conn, Commissioner, Rehabilitation Services Administration before the Committee on Labor and Human Resources, Subcommittee on the Handicapped, U.S. Senate, February 24, 1983.

33 DeJong, Independent Living, supra note 6 at 438. See also DeJong, Policy, supra note 10.

34 See DeJong, Independent Living, supra note 6 at 438; DeJong, Policy, supra note 10 at 3.

35 See DeJong, Policy, supra note 10 at 6.

36 Id.

37 See e.g., Implementing Independent Living Centers: Conference Proceedings, Edited by G. Timothy Milligan, Arkansas Rehabilitation Research & Training, 1981; Policy: Planning and Development in Independent Living, University Center for International Rehabilitation, Michigan State University June 1980.

38 Chadderdon and Malhotra, "Independent Living Centers Have Funding Problems," The Interconnector, University Center for International Rehabilitation, Michigan State University, Vol. VI, No. 1, (1982) at 10. (hereinafter Chadderdon).

39 Id.

40 Supra note 32.

41 Chadderon, supra note 38.

42 P.L. 95-602, S (a)(b)(c); 29 U.S.C. S 706, (7) (Supp. II, 1980)

43 Part A of Title VII is designed to provide subsequent direct service monies through state agencies for the delivery of independent living services by the independent living centers. Part C is designed to fund services to the elderly/ blind, and Part D to fund protection and advocacy services.

44 See Hahn, supra note 6.

45 See e.g., DeJong, Policy, supra note 10 at 6.

46 See discussion of conflict at text following footnote 31.

47 See discussion of community-responsive role of centers in text following footnote 12.

48 In each state, there are groups that undertake education, research, organizing and advocacy activities based on civil rights principles and strategy. These groups do not provide health or social services, but utilize their skills and resources to foster change in the broader social, political

and economic community in order to ensure the empowerment and integration of disabled adults and children. These groups include, among others, federally-funded state protection and advocacy offices providing legal assistance and education for developmentally disabled persons; parent-run coalitions and networks; broad-based disability rights groups with direct roots in community based independent living centers; and organizations established by and for mentally retarded and mentally disabled persons.

For example: Disability Rights Center, Washington, D.C.; Disability Rights Education and Defense Fund, Berkeley, California and Washington, D.C.; Disability Rag, Louisville, Kentucky; National Parent CHAIN, Giles, Illinois; and People First, Marin, California.

49 See DeJong, Independent Living, supra note 6 at 435.

50 Id.

51 Id. at 435-436; See also Socio-economic Status of Disabled People in the United States, Disability Rights Education and Defense Fund, August 1982.

52 Id.

53 E.g., issues involving Social Security, Voting Rights Act for Disabled and Elderly.

54 Supra notes 19 and 23.

55 See e.g., DeJong, Independent Living, supra note 6 at 445.

56 Id.

57 See DeJong, Policy, supra note 10 at 6.

58 See Milligan, supra note 36; article by Muzzio, T., "Program Evaluation for Independent Living Programs" at 54.

Appendix B.

THE INDEPENDENT LIVING LEADERSHIP STRATEGIES CONFERENCE
KELLOGG CENTER FOR CONTINUING EDUCATION
JULY 25 - JULY 30, 1982

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*Note that titles and addresses used throughout this Appendix are for positions at the time of the meeting. Participants who have changed positions are indicated by **. New addresses have been included for those who have moved to independent living/disability rights programs.

Appendix C.

Preamble and Goals

Among the foundations of our society is the acceptance of certain fundamental human rights. Independent Living is based on the belief that all individuals, including those with disabilities, shall have an equal opportunity to exercise those rights. The independent living movement shall affirm the basic human rights of disabled persons:

- To participation in the prerogative and responsibilities of citizenship
- To equal employment opportunities
- To access to public facilities, transportation and affordable housing for all disabled people
- To the supportive services necessary for employment opportunities, and full participation in society
- To free, appropriate and non-segregated education
- To bear, raise and adopt children
- To full participation in the cultural, social, recreational and economic life of the community
- To live in dignified independence outside of institutional settings

I. Services

1. Advocacy (benefit counseling)
2. Peer counseling
3. Housing assistance
4. Personal care attendant referral (specialized services)
5. Reader services/intepreters services/TTY-relay
6. Independent living skills training
7. Information and referral
8. Community education
9. Transportation
10. Legal assistance
11. Sexuality counseling
12. Recreational and leisure activities
13. Outreach
14. Equipment repair, loan and counseling
15. Services for development to achieve full human potential

II. Population and Disablilty

All segments of society shall be served.

III. Service Delivery

We affirm that because of the major importance that independent living services play on the lives of disabled people, independent living programs and services shall be controlled by and reflect the needs of the disabled community.

IV. Role of non-disabled in independent living movement

Non-disabled people shall not be at the forefront of the movement.

V. Relationship of independent living movement to civil rights movement

The independent living movement, as a direct result of the disabled people's civil rights movement, shall continue to supporty and provide leadership.

IV. Principles

1. Right to exist
2. Self-directing (individual designs services)
3. Non-medical
4. Integrationist
5. Right to choice
6. Self-determination
7. Non-residential
8. Civil rights and advocacy oriented
9. Community-based (community responsive/oriented)
10. Right to fail
11. Service with dignity
12. International human movement
13. Non-sexist and non-racist
14. Non-sectarian
15. Without regard to economic or social class
16. Non-traditional (in housing and approach)
17. Without regard to age
18. Promoting a positive and dignified image of disabled people

VII. Organizing and Coalescing

We shall encourage the development of independent living programs and organizations on the local, state, national and international levels that embrace the philosophy of the independent living movement heretoforth stated.

VIII. Ideological Leaning

Progressive thought that is dedicated to developing a peaceful and humanitarian society.

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